111TH CONGRESS 1ST SESSION

S. RES. 143

Designating May 15, 2009, as "National MPS Awareness Day".

IN THE SENATE OF THE UNITED STATES

May 12, 2009

Mr. Graham (for himself, Mr. Feingold, Mrs. Murray, Mrs. Feinstein, Mr. Conrad, Mr. Burr, Mr. Dorgan, Mr. Chambliss, Ms. Murkowski, and Ms. Collins) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating May 15, 2009, as "National MPS Awareness Day".

- Whereas mucopolysaccharidosis (referred to in this resolution as "MPS") is a genetically determined lysosomal storage disease that renders the human body incapable of producing certain enzymes needed to break down complex carbohydrates;
- Whereas complex carbohydrates are then stored in almost every cell in the body and progressively cause damage to such cells;
- Whereas such cell damage adversely affects the human body by damaging the heart, respiratory system, bones, internal organs, and central nervous system;

- Whereas the cellular damage caused by MPS often results in mental retardation, short stature, corneal damage, joint stiffness, loss of mobility, speech and hearing impairment, heart disease, hyperactivity, chronic respiratory problems, and, most importantly, a drastically shortened life span;
- Whereas the nature of the disease is usually not apparent at birth;
- Whereas, without treatment, the life expectancy of an individual afflicted with MPS begins to decrease at a very early stage in the life of the individual;
- Whereas recent research developments have resulted in the creation of limited treatments for some MPS diseases;
- Whereas promising advancements in the pursuit of treatments for additional MPS diseases are underway;
- Whereas, despite the creation of newly developed remedies, the blood-brain barrier continues to be a significant impediment to effectively treating the brain, thereby preventing the treatment of many of the symptoms of MPS;
- Whereas treatments for MPS will be greatly enhanced with continued public funding;
- Whereas the quality of life for individuals afflicted with MPS, and the treatments available to them, will be enhanced through the development of early detection techniques and early intervention;
- Whereas treatments and research advancements for MPS are limited by a lack of awareness about MPS diseases;
- Whereas the lack of awareness about MPS diseases extends to those within the medical community;

- Whereas the damage that is caused by MPS makes it a model for the study of many other degenerative genetic diseases;
- Whereas the development of effective therapies and a potential cure for MPS diseases can be accomplished by increased awareness, research, data collection, and information distribution;
- Whereas the Senate is an institution than can raise public awareness about MPS; and
- Whereas the Senate is also an institution that can assist in encouraging and facilitating increased public and private sector research for early diagnosis and treatments of MPS diseases: Now, therefore, be it
 - 1 Resolved, That the Senate—
 - 2 (1) designates May 15, 2009, as "National
 - 3 MPS Awareness Day"; and
 - 4 (2) supports the goals and ideals of "National
- 5 MPS Awareness Day".

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